# **Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics**

Established by Consensus Panel September 21-22, 2005

# **Preamble**

Genomics is a central science for all nursing practice because essentially all diseases and conditions have a genetic or genomic component. Healthcare for all persons will increasingly include genetic and genomic information along the pathways of prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.

The essential competencies were developed by an independent panel of nurses leaders from clinical, research, and academic settings whose goal was to establish the minimum basis by which to prepare the nursing workforce to deliver competent genetic and genomic focused nursing care. These competencies are not intended to replace or recreate existing standards of practice but are intended to incorporate the genetic and genomic perspective into all nursing education and practice.

The competencies were developed on the basis of:

- The results of a review of peer-reviewed published work reporting practice-based genetic and genomic competencies, guidelines, and recommendations.
- Input from nurse representatives to the National Coalition for Health Professional Education in Genetics (NCHPEG) in January, 2005.
- Public comment from the nursing community at large.
- Statements from conference attendees during open comment periods during a two day meeting of key stakeholders held September 21 and 22, 2005.

The competencies are based on the state of the evidence available at the time they were developed and reflect the **MINIMAL** amount of genetic and genomic competency expected by every nurse. These competencies reflect a consensus and are **NOT** from any Federal Agency or single Nursing Organization and are applicable to the practice of all registered nurses regardless of academic preparation, practice setting, role, or specialty.

The Nursing Organizations that have endorsed the competencies agree with the content and support and promote initiatives within their own organization to implement the competencies.

**Endorsing Organizations: To be included at a later date** 

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# **Background:**

Genetic and genomic science is redefining the understanding of the continuum of human health and illness. Therefore, recognition of genomics as a central science for health professional knowledge is essential. Because essentially all diseases and conditions have a genetic or genomic component, options for care for all persons will increasingly include genetic and genomic information along the pathways of prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness. The clinical application of genetic and genomic knowledge has major implications for the entire nursing profession regardless of academic preparation, role or practice setting.

The public will increasingly expect that the registered nurse (RN) will use genetic and genomic information and technology when providing care. These expectations have direct implications for RN preparatory curricula, as well as for the 2.5 million practicing nurses. The rate of progress for applying a genomic approach throughout the continuum of care depends not only on technologic advances, but also on nursing expertise. In its report on genetics and nursing in 2000, an expert Health Resources and Services Administration (HRSA) panel emphasized the importance of integrating genetics content into nursing curricula in order to provide an adequately prepared nursing workforce now and for the future<sup>1</sup>. To care for persons/families/communities and/or populations throughout the lifespan, the registered nurse will need to demonstrate proficiency with incorporating genetic and genomic information into their practice. For example:

- understand the genetic and genomic basis of health and/or an illness for which the person is seeking care and the variables that impact their response
- recognize a newborn at risk for morbidity or mortality resulting from genetic metabolism errors
- identify an asymptomatic adolescent who is at high risk for hereditary colon cancer
- identify a couple at risk for having a child with a genetic condition
- guide interventions for the prevention of cardiovascular disease in young adults
- facilitate drug selection or dosage in treatment of an adult with cancer based on molecular markers
- promote informed consent that includes the risks, benefits and limitations of participation in genetic research
- assist anyone having questions about genetic and genomic information or services
- identify Caucasians of northern European descent (a population at risk for hemachromatosis) who have joint disease, severe and continuing fatigue, heart disease, elevated liver enzymes, impotence, and diabetes, because they are candidates for *HFE* genetic testing.

#### **Purpose:**

The primary purpose of this document is to define essential genetic and genomic competencies for all registered nurses. This document is intended to guide nurse educators in the design and implementation of learning experiences that help students/learners/practicing nurses achieve these genetic and genomic competencies. These competencies are not intended to replace or recreate existing standards of practice but are intended to incorporate the genetic and genomic

perspective into all nursing education and practice. The goal is to prepare the nursing workforce to deliver competent genetic and genomic focused nursing care.

### **Definitions:**

**Genetics** – study of individual genes and their impact on relatively rare single gene disorders<sup>2</sup>

**Genomics** – study of all the genes in the human genome together, including their interactions with each other, the environment, and the influence of other psychosocial and cultural factors<sup>2</sup>

These two definitions remain a work in progress because the new knowledge produced by genome research will create an ongoing need to assess and revise our understanding of the influence of genetic and genomic factors for health outcomes. For the purpose of this document, both genetic and genomic information will be used as the context for defining required competencies.

**Clients** – Recipients of healthcare may include persons, families, communities, and/or populations from any race, ethnicity/ancestry, culture or religious background. The term clients will be used throughtout the document to reflect the focus of nursing care.

**Services** – The delivery of genetic and genomic healthcare.

**Resources** – A collection of genetic and genomic tools and sites for healthcare referrals for delivery of nursing care.

**Technology** – The use of tools and/or machines to perform tasks. In this case the identification and assessment of genetic and genomic information (e.g. the use of micoarray technology to assess the genetic features of a specific tumor).

**Pedigree** – A graphic illustration of a family health history using standardized symbols<sup>3</sup>.

#### **Applicability:**

The genetic and genomic competencies are integral to the practice of all registered nurses regardless of academic preparation, practice setting, role, or specialty.

### **History of Development:**

**Resource/Reference Documents** – The Steering Committee identified, reviewed, analyzed, and compared competencies recommended in existing published and peer reviewed documents<sup>4-12</sup>. A pre-publication manuscript by K. Greco<sup>13</sup> reported on a qualitative analysis of published competency recommendations, including many of the above documents<sup>4, 5, 8, 9</sup>. In addition, a competence-based education framework developed in the United Kingdom was used as a resource document<sup>14</sup>. Analysis of these documents and resources identified fundamental genetic and genomic competencies applicable for all registered nurses. A summary of available resources are provided in Appendix A.

Competency Development – Based on the review of earlier peer-reviewed published work reporting practice-based genetic and genomic competencies, guidelines, and recommendations, a group of nurse leaders from clinical, research, and academic settings developed these proposed competencies. The proposed competencies were approved by a steering committee of federal, academic and national leaders in nursing. In addition, these competencies were reviewed by nurse representatives to the National Coalition for Health Professional Education in Genetics (NCHPEG) in 2005 with subsequent revision to integrate their comments. To assist the development process, public comments, especially from the nursing community, were solicited.

#### **Process of Consensus**

Phase 1 The Steering Committee reviewed and provided comments on the preliminary document. This revised draft document was shared with nursing representatives attending the National Coalition for Health Professional Education in Genetics Meeting (January 2005) to further define and structure these recommended essential nursing competencies in genetics and genomics.

Phase II Additional review of the revised essentials document commenced with the posting for public comment at <a href="http://NursingWorld.org/practice">http://NursingWorld.org/practice</a> and announcement to the American Nurses Association (ANA) and its constituent members and organizational affiliates, the Nursing Organizations Alliance, and other nursing organizations. All comments were carefully considered and appropriate revisions incorporated as indicated. Endorsement of the final document by these organizations will be requested by March 2006.

Phase III A meeting of key stakeholders was held September 21 & 22, 2005 to establish consensus on the final competency document by key stakeholders. See Appendix B for the list of meeting participants. Strategies to integrate genetic and genomic information into education and practice were proposed and then discussed, with identification of steps to include in an action plan for integration of recommended genetic and genomic nursing competencies content into curricula, the NCLEX examination, specialty certification processes, and accreditation programs.

# **Essential Competencies**

# **Professional Responsibilities**

All registered nurses are expected to engage in professional role activities that are consistent with the Nursing: Scope and Standards of Practice, 2004 by the American Nurses Association<sup>15</sup>. In addition, competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills in order to:

- Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients
- Advocate for clients access to desired genetic/genomic services and/or resources
- Examine competency of practice on a regular basis, identifying areas of strength, as well
  as areas in which professional development related to genetics and genomics would be
  beneficial
- Incorporate genetic and genomic technologies and information into registered nurse practice
- Demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy and preferred language
- Advocate for the rights of all clients for autonomous, informed genetic and genomicrelated decision-making and voluntary action

#### **Professional Practice Domain**

# Nursing Assessment applying/integrating genetic and genomic knowledge

# The registered nurse:

- Demonstrates an understanding of the relationship of genetics/genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness
- Demonstrates ability to elicit a minimum of three generation family health history information
- Constructs pedigree from collected family history information using standardized symbols and terminology
- Collects personal, health and developmental histories that consider genetic, environmental, and genomic influences and risks
- Conducts comprehensive health and physical assessments that incorporates knowledge about genetic, environmental, and genomic influences and risk factors
- Critically analyzes the history and physical assessment findings for genetic, environmental, and genomic influences and risk factors
- Assesses clients' knowledge, perceptions, and responses to genetic and genomic information
- Develops plan of care that incorporates genetic and genomic assessment information

#### Identification

# The registered nurse:

- Identifies clients who may benefit from specific genetic and genomic information and/or services based on assessment data
- Identifies credible, accurate, appropriate and current genetic and genomic information, resources, services and/or technologies specific to given clients
- Identifies ethical, ethnic/ancestral, cultural, religious, legal, fiscal, and societal issues related to genetic and genomic information and technologies
- Defines issues that undermine the rights of all clients for autonomous, informed genetic and genomic-related decision-making and voluntary action

#### **Referral Activities**

# The registered nurse:

• Facilitates referrals for specialized genetic and genomic services for clients as needed

# **Provision of Education, Care & Support**

# The registered nurse:

- Provides clients with interpretation of selective genetic and genomic information or services
- Provides clients with genetic and genomic credible, accurate, appropriate and current information, resources, services and/or technologies that facilitate decision-making
- Uses health promotion/disease prevention practices that:
  - o Considers genetic and genomic influences on risk with personal and environmental risk factors
  - o Incorporates knowledge of genetic and/or genomic risk factors (e.g., a client with a genetic predisposition for high cholesterol that can benefit from a change in lifestyle that will decrease the likelihood that the genetic risk will be expressed)
- Uses genetic and genomic-based interventions and information to improve clients' outcomes
- Collaborates with healthcare providers in providing genetic and genomic health care
- Collaborates with insurance providers/payers to facilitate reimbursement for genetic and genomic health care services
- Performs interventions/treatments appropriate to clients' genetic and genomic health care needs
- Evaluates impact and effectiveness of genetic and genomic technology, information, interventions, and treatments on clients' outcome

# **Essential Competencies**

# **Strategies:**

Practice and curriculum change requires the commitment of nursing leaders and academic faculty to develop a long-term plan to incorporate genetic and genomic information to improve the public's health. Faculty and practicing nurses must be supported to attend continuing education or academic courses to update their genetic and genomic knowledge. Collaboration with other disciplines is necessary to provide a strong foundation of knowledge of basic human genetics and current applications to practice.

NCLEX – Participate in the NCLEX test development process to ensure inclusion of test items addressing genetic and genomic knowledge. Continue to include and participate in development of test items assessing integration of genetic and genomic knowledge. Work with the American Hospital Association and other regulatory agencies/organizations to incorporate genetics and genomics practice content on assessments of quality which will also influence NCLEX content.

**Certification** – All certification exams should include test items measuring the knowledge of genetic and genomic information pertinent to the specialty for which a registered nurse is being certified.

**Practicing Nurses** – Practicing nurses should be encouraged to pursue genetic and genomic continuing education. Consider establishing a United States National Genetics Education and Development Center modeled after the United Kingdom initiative which can serve as the central resource for genetics and genomic education initiatives. <a href="http://www.geneticseducation.nhs.uk">http://www.geneticseducation.nhs.uk</a>

**Accreditation of Programs** – The standards for accreditation should evaluate whether the curriculum is designed to meet the essential core genetic and genomic competencies. http://www.nlnac.org/manuals/NLNACManual2004.pdf

**Curricula** – Each nursing curriculum preparing registered nurses for practice (at any and all levels) should include genetic and genomic learning experiences sufficient for all registered nurses to be proficient in the essential competencies. This can be accomplished by incorporating genetics and genomics learning experiences into existing classes. Refer to Appendix A for resources useful to faculty.

# **Incorporating Competencies, Content, and Teaching Strategies in the Curriculum:**

Today's nursing curriculum is dense and integrating new information is a challenge. Since genetic and genomic information is integral and critical to all areas of nursing practice, curricula must prepare graduates with this information <sup>16</sup>. Nursing faculty from 171 nursing schools contributed to the development of a checklist which was created to help faculty integrate genetics content into nursing curricula<sup>17</sup>. An important initial strategy noted in the checklist is to determine what content is already being taught in pre-nursing and nursing courses. Once content gaps are identified, many curriculum change strategies can be used to add genetic and genomic content to instructional resources<sup>18</sup>. Potential solutions include incorporating genetics and genomics as a central science including the following:

- add genetic and genomic content to existing lectures,
- integrate assignments incorporating genetic and genomic knowledge and test questions to existing courses,
- include genetic and genomic-focused objectives to all nursing courses,
- create a curriculum thread focused on genetics and genomics,
- develop an elective genetics and genomics nursing course that can be transitioned into a required course, and
- collaborate with interdisciplinary colleagues to design courses and curricula.

Outcomes associated with some of the curriculum options listed above have already been published<sup>19</sup>. A theory based approach to integrating genetics into one school's nursing curriculum is well described by Horner et al<sup>20</sup>. Integrative approaches in associate and baccalaureate programs have been published by Danz, 2004, Zamerowski, 2000, and Read et al., 2004<sup>21, 22, 23</sup>. Development of a single genetic and genomic nursing course incorporated into the curriculum has also been described<sup>24</sup>. The ability of faculty to effectively incorporate genetics and genomics content into the nursing curricula hinges on the availability of faculty with education or expertise in genetics and genomics<sup>25</sup>. Outcomes associated with faculty training initiatives addressing this need (including summer institutes and a web based program<sup>26, 27, 28</sup>) have also been described.

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# Appendix A: Resources

# Clinical Genetic Resources

Resource	Contact	Description
GeneTests	http://www.genetests.	Information for health
	org/	professionals about
		hundreds of genetic
		tests and the
		laboratories
		performing those tests
Human Genome Epidemiology Network	http://www.cdc.gov/g	Network for sharing
(HuGENet)	enomics/hugenet/defa	population-based
	<u>ult.htm</u>	human genome
		epidemiologic
		information
INFOGENETICS	http://www.infogeneti	Clinical practice tools
	cs.org/	
National Birth Defects Prevention Network	http://www.nbdpn.org	Network of birth
		defect care providers
National Newborn Screening & Genetics	http://www.genes-r-	National Newborn
Resource Center	us.uthscsa.edu/	Screening & Genetics
		Resource Center
Online Mendelian Inheritance in Man	http://www.ncbi.nlm.	Information about
(OMIM)	nih.gov/Omim/	human genes and
		disease

**Support and Advocacy Groups** 

Resource	Contact	Description
Coalition for Genetic Fairness	http://www.geneticfai	Advocacy group for
	rness.org/	federal legislation
		regarding genetics
		discrimination
Family Village	http://www.familyvill	Disability-related
	age.wisc.edu/index.ht	resources
	<u>mlx</u>	
The Genetic Alliance	http://www.geneticalli	Wide array of
	ance.org/	genetic-related
		information
The Genome Action Coalition	http://www.tgac.org	Advocacy group for
		federal genetic
		legislation
National Organization for Rare Disorders	http://www.rarediseas	Wide array of
	es.org/	genetic-related
		information

# **Health Professional Genetic Resources**

Resource	Contact	Description
Clinical Genetics: A Self Study for Health	http://www.vh.org/pe	Electronic textbook
Care Providers	diatric/provider/pediat	from Virtual
	rics/ClinicalGenetics/	Children's Hospital
	Contents.html	_
Foundation for Genetic Education and	http://www.fgec.org	Genetics and common
Counseling		diseases, especially
		psychiatric disorders
Genetics and Your Practice Online	http://www.marchofdi	A practical "how-to"
	mes.com/gyponline/in	
	dex.bm2	genetics from the
		March of Dimes
Genetics in Clinical Practice: A Team	http://iml.dartmouth.e	
Approach	du/education/cme/Gen	Clinic
	etics/	
Genetics in Primary Care	http://genes-r-	Training program
	us.uthscsa.edu/resourc	curriculum materials
	es/genetics/primary_c	
	are.htm	
Genetics in Psychology	http://www.apa.org/sc	
	ience/genetics/homep	•
	age.html	Association's site
		about genetics
Genetics Program for Nursing Faculty	http://www.gpnf.org	Links to genetics
		resources of particular
		interest to nurses
Genetics: Educational Information	http://www.faseb.org/	Medical school
	genetics/careers.htm	courses in genetics,
		some with syllabi
Information for Genetics Professionals	http://www.kumc.edu/	Educational, clinical,
	gec/geneinfo.html	and research
		resources
National Coalition for Health Professional	http://www.nchpeg.or	Core competencies in
Education in Genetics	<u>g/</u>	genetics and reviews
		of education
		programs

# **IRB Related Resources**

Resource	Contact	Description
My Very Own Medicine: What Must I	http://www.phgu.org.	General information and
know? Information Policy for	uk/about_phgu/pharm	background, looking
Pharmacogenetics. Public Health Genetics	acogenetics.html	ahead to future needs,
Unit, National Health Service, UK - D.		including guidance for
Melzer et al. (2003).		IRBs
New York State Task Force on Life and	http://www.health.stat	Includes general and state
Law: Genetic Testing and Screening in the	e.ny.us/nysdoh/taskfc	specific information in a
Age of Genomic Medicine (2001).		bulleted report that is
		relatively easy to scan by
		topic
Office for Human Research Protections:	http://www.hhs.gov/o	Discusses many issues
Protecting Human Research Subjects	hrp/irb/irb_chapter5ii.	that continue to challenge
Institutional Review Board Guidebook,	htm#h12	IRBs and investigators
Chapter H: Human Genetic Research		(and policy makers)
(1993).		today
Pharmacogenetics: Ethical Issues. Nuffield	http://www.nuffieldbi	Includes a section
Council on Bioethics (2003).	oethics.org/publicatio	discussing the use of
	ns/pp_000000018.as	pharmacogenetics in
	<u>p</u>	clinical trials

**Search Engines** 

caren Engines		
Resource	Contact	Description
Centers for Disease Control: Genomics and	http://apps.nccd.cdc.g	Provides access to
Disease Prevention Information System	ov/genomics/GDPque	information and resources
	rytool/searchbygene.a	for guiding public health
	<u>sp</u>	research, policy, and
		practice on using genetic
		information to improve
		health and prevent
		disease. Includes core
		competencies for public
		health genetics.
Georgetown University: National	http://www.georgetow	Search engine for
Information Resource on Ethics & Human	n.edu/research/nrcbl/n	literature on specific
Genetics	irehg/index.htm	issues
National Newborn Screening and Genetics	http://www.gemdatab	Search engine for clinical
Resource Center: Genetic Education	ase.org/GEMDatabase	issues
Materials Database	<u>/index.asp</u>	

Genetics Resources on the Web (GROW)	http://www.geneticsre	Provides health
	sources.org/	professionals and the
		public with high quality
		information related to
		human genetics, with a
		particular focus on
		genetic medicine and
		health

# **Genetics Instructional Resources**

Resource	Contact	Description
GEPN curriculum resources	www.gepn.cchmc.o	Sample genetics
	<u>rg</u>	nursing course syllabi;
		links to instructional
		resources used in GSI
		and WBGI
Self-paced genetics modules based on	www.gepn.cchmc.o	Designed for practicing
NCHPEG competencies	<u>rg</u>	nurses; however, each
		module could be
		assigned to students to
		learn a particular topic.
		Access and use is free.
Practice-Based Genetics Curricula for	www.fbr.org	Bound instructional
Nurse Educators		modules with
		accompanying CD or
		PowerPoint
		presentations
Genetics and Your Practice Online	http://www.marcho	Online modules
	fdimes.com/gyponli	designed for
	ne/index.bm2	exploration of a topic
		rather than sequential
		presentation of
		material. Many
		excellent fact sheets &
		sample clinical forms
Genetics in Clinical Practice – A Team	http://www.acmg.n	Interactive CD-ROM,
Approach	et/resources/cd-	virtual genetics clinic
	rom-01/intro.asp	with case scenarios and
		case discussions.
		Target audience is
		primary care
		professionals.

Dolan DNA Learning Center	http://www.dnalc.or	Interactive, multimedia genetics education resources
National Cancer Institute's CancerNet	http://www.cancer. gov/cancerinfo/prev ention-genetics- causes	Authoritative information about cancer genetics
National Coalition of Health Care Professionals (NCHPEG) education resources	http://www.nchpeg. org	Descriptions of available instructional resources, courses, institutes. All have been submitted by developers and some have accompanying peer reviews
Kansas Genetics Education Center	http://www.kumc.e du/gec/	An ever growing list of available resources
Centre for Genetics Education	http://www.genetics .com.au/	Education and service resources for patients and professionals
GenEd Project	http://www.medicin e.man.ac.uk/GenEd /	Education and research links related to European aspects of genetic services
Centre for Education in Medical Genetics	http://www.bwhct.n hs.uk/cemg/index.h tm	Develop, provide and evaluate genetics education opportunities and resources
Six Weeks to Genomic Awareness	http://www.genomi cawareness.org/	Webcast of 12 segments of genomic topics
Physician's Database Query (PDQ®)	http://www.cancer. gov/cancerinfo/pdq/ genetics	PDQ® cancer information summaries in genetics

**Organizational Resources to Guide Nursing Practice** 

Organization	urces to Guide Nursing Fracti	Material
American Nurses	http://www.nursingworld.org	Code of Ethics for Nurses
Association	intep.// www.narsingworld.org	<ul><li>Policy statements on</li></ul>
7105001441011		genetics and nursing:
		Cloning and therapeutic and
		reproductive application of
		genetics
		<ul><li>Position statements on</li></ul>
		human cloning: human
		rights, discriminations and
		privacy and confidentiality
Amarican Cociety of	http://xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx	
American Society of	http://www.asco.org	Policy Statement Update:
Clinical Oncology		Genetic testing for cancer
		susceptibility
Association of	http://www.awhonn.org	Position Statement: The
Women's Health,		role of the registered nurse
Obstetric and		as related to genetic testing
Neonatal Nurses		
Department of	http://www.os.dhhs.gov/	Report of the expert panel
Health and Human		on genetics and nursing:
Services		Implications for education
		and practice
International Society	http://www.isong.org	<ul> <li>Statement on the scope</li> </ul>
of Nurses in		and standards of genetics
Genetics, Inc.		clinical nursing practice
		<ul><li>Position statement:</li></ul>
		Access to genomic
		healthcare: The role of the
		nurse
		<ul> <li>Position statement.</li> </ul>
		Privacy and confidentiality
		of genetic information: The
		role of the nurse
		Position statement:
		Genetic counseling for
		vulnerable populations:
		The role of nursing
		Position statement:
		Informed decision-making
		and consent: The role of
		nursing
National Coalition of	http://www.nchpeg.org	Recommendations of core
Health Care		competencies in genetics for
Professionals		all health professionals

Oncology Nursing	http://www.ons.org	• Position statement: The
Society		role of the oncology nurse
		in cancer genetic counseling
		• Position statement:
		Cancer predisposition
		genetic testing and risk
		assessment counseling

# **Professional Genetic Education Resources**

Organization	Contact Information	Program/Resources
Academic-Nursi	ng	
Columbia University	Columbia University School of Nursing 630 West 168th Street New York, NY 10032 (212) 305-5756 <a href="http://www.cumc.columbia.edu/dept/nursing/programs/cg.html">http://www.cumc.columbia.edu/dept/nursing/programs/cg.html</a>	Masters degree program with a clinical genetics sub-specialty
University of Iowa	University of Iowa Iowa City, IA 52242 319-335-7046 Attention: Janet Williams, PhD, RN http://www.uiowa.edu	Masters and PhD degree programs in genetic nursing
University of Pittsburgh	University of Pittsburgh School of Nursing 239 Victoria Building Pittsburgh, PA 15261 412-624-4586 or 1-888-747-0794 http://www.pitt.edu/~nursing/academicprog rams/certificates/post_bacc_genetics.html and http://www.pitt.edu/~nursing/academicprog rams/certificates/post_masters_cert_genetic s.html	Post-Baccalaureate Certificate in Genetics Post-Master's Certificate in Health Care Genetics
University of California, San Francisco	University of California, San Francisco Department of Physiological Nursing 2 Koret Way, Suite N631 San Francisco, CA 94143-0610 415-476-0984 Attention: Mary B. Engler, PhD, RN, MS http://nurseweb.ucsf.edu/www/genomic.htm	Masters degree program in nursing genetics
University of Washington	University of Washington School of Nursing Box 357260 Seattle, WA 98195 206-221-2458 <a href="http://www.son.washington.edu/eo/apgn">http://www.son.washington.edu/eo/apgn</a>	Masters degree program with a minor in genetics nursing

Continuing Education		
American	1900 Duke Street Suite 200	Cancer Genetics and
Society of	Alexandria, VA 22314	Cancer Predisposition
Clinical	703-299-0150	Genetic Testing, 1st
Oncology	http://www.asco.org	Edition-An ASCO
83		Curriculum including
		binders and CDRom
		slide set.
		ONCOSEP: Genetics-
		Tool for self-education
		and assessment in
		genetic testing, risk
		assessment, and specific
		areas of genetic disease.
Cincinnati	3333 Burnet Avenue	Genetics Education
Children's	Cincinnati, Ohio 45229-3039	Program for Nurses-
Hospital	513-636-4200	Web Based Genetics
Medical Center	http://www.cincinnatichildrens.org/ed/clinic	Institute and
	<u>al/gpnf</u>	
		Genetics Education
		Program for Nursing
		Faculty
City of Hope	1500 E. Duarte Road	Intensive Course in
National	Duarte, CA 91010-3000	Cancer Risk Assessment
Medical Center	800-423-7119	
and Beckman	http://www.cityofhope.org	
Research		
Institute	COLUMB	D i D IG
Foundation for	69 US Route 1	Practice-Based Genetics
Blood	P.O. Box 190	Curriculum For Nurse
Research	Scarborough ME 04070-0190	Educators
	207-883-4131	
Fox Chase	http://www.fbr.org 333 Cottman Avenue	A Basic Course in
Cancer Center		Cancer Genetics:
Cancer Center	Philadelphia, PA 19111-2497 215-728-2892	Familial Cancer Risk
	http://www.fccc.edu/nursing/education/	Assessment
	intp.// www.rece.edu/nursing/education/	1 MOCOMITOR
		An Advanced Training
		for Nurses in Cancer
		Risk Counseling

International	461 Cochran Road	Annual Nursing and
Society of	Box 246	Genetic Education
Nurses in	Pittsburgh, PA 15228	Meeting
Genetics, Inc.	412-344-1414	
(ISONG)	Email: <u>isongHQ@msn.com</u>	Statement on the Scope
	http://www.isong.org	and Standards of
		Clinical Genetics
		Nursing Practice
National	Summer Genetics Institute	Summer Genetics
Institute of	Division of Intramural Research	Institute
Nursing	National Institute of Nursing Research	
Research	National Institutes of Health	
(NINR)	31 Center Drive, 5B-13	
	Bethesda, MD 20892-2178	
	http://www.nih.gov/ninr/research/dir/sgi.ht	
	<u>ml</u>	
Oncology	125 Enterprise Drive	Genetics Short Course
Nursing	RIDC Park West	for Oncology Nurses
Society (ONS)	Pittsburgh, PA 15275-1214	
	866-257-4ONS	
	Email: <u>customer.service@ons.org</u>	
	http://www.ons.org	

# **Consumer Resources**

Consumer Resources		T
Resource	Contact	Description
Building and Understanding Your Medical	http://jamesline.com/p	Information on
Family History	atientsandvisitors/prev	collecting family health
	ention/cancergenetics/	history and assessing
		cancer risk
The DNA Files	http://www.dnafiles.or	A series of 14 one-hour
	<u>g/</u>	public radio
		documentaries and
		related information
Dolan DNA Learning Center	http://vector.cshl.org/	A variety of educational
		resources, including an
		interactive DNA
		timeline
Foundations of Classical Genetics	http://www.esp.org/fo	Complete versions of
	undations/genetics/cla	classic genetics works
	<u>ssical</u>	written between 350
		A.D. and 1932

Generational Health	http://www.generation	Tool to halp trace a
Generational Health	_	family's medical history
	ameann.com/	and provide
		information on
	1.,, // 1	common diseases
Genetic Science Learning Center		Basic genetics, genetic
	<u>h.edu/</u>	disorders, genetics in
		society, and several
		thematic units
Genetics and Rare Diseases Information		Information service for
Center	ov/10000409	the general public,
		including patients and
		their families, health
		care professionals and
		biomedical researchers
Ethics and Genetic Testing for Nurses	http://www.nursing.ui	CDROM-3 module on
	owa.edu/areas/parentc	ethics, on genetic
	hild/cdrom.htm	testing, case studies
Genetics Education Center	http://www.kumc.edu/	Material for educators
	gec/	
Genetics Home Reference- National Library	http://ghr.nlm.nih.gov	Consumer information
of Medicine	/	about genetic
		conditions and the
		genes responsible for
		those conditions
The Human Genome Project: Exploring	http://www.genome.g	Video about Human
Our Molecular Selves	ov/Pages/EducationKi	
	t/	timeline about genetics,
		talking glossary,
		classroom activities, 3-
		D animation of cell
MendelWeb	http://www.mendelwe	
IVICITACI VV CO	b.org/	English and German
	<u>0.01<u>g</u>/</u>	and related materials
National Society for Genetic Counselors-	http://www.nsgc.org/c	
•		
Family History		collecting family health
The New Constinut A Descript for Constinute		history
The New Genetics: A Resource for Students		
and Teachers	u/camlbweb/teachgen.	education resources
	<u>html</u>	

Understanding Gene Testing	http://www.cancer.go Primer on genetic
	v/cancertopics/Unders testing
	tandingCancer/genete
	sting

**ELSI, Policy and Legislation** 

Resource	Contact	Description
American Academy of Pediatrics: Ethical	http://pediatrics.aappu	Recommendations on
Issues With Genetic Testing in Pediatrics		newborn screening and
	cription/full/107/6/14	
	51	children
Bioethics Resources on the Web	http://www.nih.gov/si	Links to bioethics
	gs/bioethics/	resources
bioethics.net	http://www.bioethics.	Links to articles on
	net/genetics/genetics.	bioethics and genetics
	<u>php</u>	
DNA Patent Database	http://dnapatents.geor	Searchable database of
	getown.edu	U.S. DNA-based
		patents issued by the
		USPTO
The Council for Responsible Genetics	http://www.gene-	Information on the
	watch.org/	social, ethical and
		environmental
		implications of genetic
		technologies
Ethical, Legal, & Social Issues	http://www.ornl.gov/h	
	gmis/elsi/elsi.html	and links on a wide
	http://www.genome.g	range of issues
	ov/10001754	
Foundation for Genetic Medicine, Inc.	http://www.geneticme	
	dicine.org/	science of genetic
		medicine, genetic and
		genomic research, and
		ethical, legal and social
		dimensions and
		implications
Genetics & Ethics		Information on the
	ca/index.html	social, ethical and
		policy issues associated
		with genetic and
		genomic knowledge
		and technology

Genetics and the Law	http://www.genelaw.i	A searchable online
Genetics and the Law	nfo/	clearinghouse of
	<u> </u>	information on
		emerging legal
		developments in human
		_
Canatias and Dublia Daliay Cantar	www.dnonoliov.org	genetics
Genetics and Public Policy Center	www.dnapolicy.org	Information on genetic
		technologies and
		genetic policies for the
		public, media and
	1 // 1 .1	policymakers
Genome Technology and Reproduction:	http://www.sph.umich	
Values and Public Policy and The	.edu/genpolicy/	combined to form a five
Communities of Color & Genetics Policy		year project designed to
Project		provide policy
		recommendations based
		on public perceptions
		and responses to the
		explosion of genetic
		information and
		technology.
HumGen	http://www.humgen.u	Access to a
	montreal.ca/en/	comprehensive
		international database
		on the legal, social and
		ethical aspects of
		human genetics
National Information Resources on Ethics &	khttp://www.georgetow	Links to resources on
Human Genetics	n.edu/research/nrcbl/n	ethics and human
	irehg/index.htm	genetics
NCSL- Genetic Technologies Project	http://www.ncsl.org/p	Status of legislative
	rograms/health/geneti	actions and access to
	cs.htm	policy briefs on genetic
		issues of concern to
		state legislators
The President's Council on Bioethics	http://www.bioethics.	Information on current
	gov/	bioethical issues
Scope Note Series (Kennedy Institute of	http://www.georgetow	Information on various
Ethics/ Georgetown University)		aspects of genetics and
	irehg/scope.htm	ethics
THOMAS Legislative Information on the	http://thomas.loc.gov/	Searchable database of
Internet		U.S. legislation
i	_1	

Your Genes Your Choices	http://ehrweb.aaas.org	Describes the Human
	/ehr/books/index.html	Genome Project, the
		science behind it, and
		the ethical, legal, and
		social issues that are
		raised by the project

**Genetics Professional Groups** 

Resource	Contact	Description
American Board of Genetic Counseling	http://www.faseb.org/	Information about
		certification of genetic
	<u>nu.htm</u>	counselors
American Board of Medical Genetics	http://www.faseb.org/	Information about
	genetics/abmg/abmgm	medical genetic training
	enu.htm	programs and
		certification of
		geneticists
American College of Medical Genetics	http://www.acmg.net/	Information and policy
		statements about
		medical genetics
American Society for Human Genetics	http://www.ashg.org/	Information about
		human genetics
Genetics Nursing Credentialing	http://www.geneticnu	Information about
Commission	se.org	credentialing of genetic
		nurses
Genetics Society of America	http://www.faseb.org/	Information about
	genetics/gsa/gsamenu.	genetics
	<u>htm</u>	
International Society of Nurses in Genetics	http://www.isong.org/	Information about
		genetics in nursing
National Society of Genetic Counselors	http://www.nsgc.org/	Information about
		genetic counseling
Society for the Study of Inborn Errors of	http://www.ssiem.org/	Information about
Metabolism		inborn errors of
		metabolism

**United States Government Genetic Agencies** 

Resource	Contact	Description
Center for Disease Control and Prevention,	http://www.cdc.gov/g	Information about
Office of Genomics & Disease Prevention	enomics/default.htm	human genetic
		discoveries and how
		to use to improve
		health and prevent
		disease

Department of Energy	http://www.doegenom	Multiple genetics
Department of Energy	es.org/	educational resources
Genetic Modification Clinical Research	http://www.gemcris.o	
Information System (GeMCRIS)	d.nih.gov/	information about
information System (Genterals)	d.mn.gov/	human gene transfer
		trials registered with
		the NIH
Health Resources and Services	http://www.mchb.hrsa	
Administration- Genetics Services Branch	-	mission to improve
Administration- Genetics Services Branch	<u>.gov/</u>	and expand access to
		_
		quality healthcare for all
National Cancer Institute's CancerNet	http://www.cancer.go	Authoritative
Trational Cancer Institute's Cancerret	v/cancerinfo/preventio	
	n-genetics-causes	cancer genetics
National Human Genome Research Institute		Research, health,
Transmit Genome Research Institute	ov	policy, ethics,
		education, and
		training information
		and resources
National Institute of Environmental Health	http://www.niehs.nih.	Project to improve
Sciences- Environmental Genome Project	-	understanding of
Sciences- Environmental Genome Project	htm	human genetic
	11(111	susceptibility to
		environmental
		exposures
National Institutes of Health Obesity	http://obesityresearch.	-
Research	nih.gov/	NIH-supported
	<u> </u>	research that seeks to
		identify genetic,
		behavioral, and
		environmental causes
		of obesity
National Institutes of Health	http://www.nih.gov/	Research, health,
Transfer Institutes of Treatur	ittp://www.imi.gov/	policy, ethics,
		education, and
		training information
		& resources
National Institute of Nursing Research-	http://fmp.cit.nih.gov/	Summer Genetics
Summer Genetics Institute	ninr/	Institute program that
		is designed to provide
		training in molecular
		genetics for use in
		research and clinical
		practice
	l	practice

Office of Rare Diseases, National Institutes	http://rarediseases.inf	Information on
of Health	o.nih.gov/	thousands of rare
		disorders
Secretary's Advisory Committee on Genetic	http://www4.od.nih.g	Policy issues
Testing	ov/oba/SACGT.HTM	regarding genetic
		testing (archival)
Secretary's Advisory Committee on	http://www4.od.nih.g	Policy issues
Genetics, Health, and Society	ov/oba/sacghs.htm	regarding the impact
		of genetic
		technologies on
		society

**Family History Tools** 

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Resource	Contact	Description	
American Medical Association- Family	http://www.ama-	Tools for gathering	
History Tools	assn.org/ama/pub/cate	family history	
	gory/2380.html		
Cyrillic	www.cyrillicsoftware.	Pedigree drawing	
	<u>com</u>	software	
Pedigree Draw	http://www.pedigree-	Pedigree drawing	
	draw.com	software	
Progeny	www.progeny2000.co	Pedigree drawing	
	<u>m</u>	software	
U.S. Surgeon General Family History	http://www.hhs.gov/fa	Patient completed	
Initiative	milyhistory/	pedigree drawing	
"My Family Health Portrait"		software	

Sites that Track or Report on What's New in Genetics

Resource	Contact	Description
Genetics and Molecular Medicine	http://www.ama-	Links to current
(American Medical Association)	assn.org/ama/pub/cate	articles and other
	gory/1799.html	resources
Genome News Network (The Center for the	http://www.genomene	Original articles and
Advancement of Genomics)	wsnetwork.org/main.s	links
	<u>html</u>	
Science News Presented by BIO:	http://science.bio.org/	Links to current
Biotechnology Industry Organization	genomics.news.html	articles

# **Risk Assessment**

Resource	Contact	Description
Harvard Center for Cancer Prevention-	http://www.yourcance	Personalized
Your Cancer Risk	rrisk.harvard.edu/	estimation of cancer
		risk and tips for
		prevention

National Cancer Institute- Breast Cancer	http://bcra.nci.nih.gov	Interactive tool to
Risk Assessment Tool	<u>/brc/</u>	measure a woman's
		risk of invasive breast
		cancer

**Resource Genetic and Genomic Books and Monographs** 

Resource Genetic and Genomic Books and		
Resource	Publisher	Description
Clinical Genetics in Nursing Practice 3 <sup>rd</sup>	Springer Publishing	Nursing and genetics
Edition (2005)	Company, Inc.	text
By Felissa Lashley		
Nursing and 21 <sup>st</sup> Century Genetics:	International Council of	The monograph is
Leadership for Global Health (2004)	Nurses	comprehensive in its
Editors Suzanne Feetham, Janet Williams	http://www.icn.ch/books	coverage of genetics
	hop.htm	from diverse cultural
		and religious
		perspectives, it is
		applicable and
		appealing to nurses
		worldwide. Key
		issues covered
		include: leadership in
		genetic education,
		genetic nursing
		practice, nursing
		informatics and
		genetics health,
		genetic research in
		nursing and nursing
		leadership to address
		ethical challenges in
		genetics.
Genetics in Oncology Practice: Cancer Risk		A detailed overview
Assessment (2003)	Press	of genetics and the
Editors Amy Strauss Tranin, Agnes Masny,		implications for
Jean Jenkins		cancer nursing
		practice
The Genetics Revolution: Implications for	American Nurses	The first nursing
Nurses (1997)	Association	monograph to be
By Felissa Lashley		published on the
		profession's responses
		to the opportunities
		and challenges of the
		Human Genome
		Project and the
		advances in gene
		research.

Applied Genetics in Healthcare (2005) By Heather Skirton, Christine Patch, Janet Williams	BIOS Scientific Publishers	Test for application of genetic and genomic principles by nurses who provide genetic and genomic health care as specialist practitioners and advanced practice nurses
Nursing Care in the Genomic Era: A Case Based Approach (2005) By Jean Jenkins, Dale Lea	Jones & Bartlett Publishers	Provides nurses with up-to-date and accessible information on core competencies in genetics, interwoven with stories that highlight a particular condition and the related biological, personal, and psychosocial issues.
Genetics in Clinical Practice: New Directions for Nursing and Health Care (1998) By Dale Lea and Jean Jenkins	Jones & Bartlett Publishers	Provides a unique, understandable approach to the emerging science of genetics
Genetic Nursing Portfolios: A New Model for the Profession (2005) Editor: Rita Black Monsen	American Nurses Association	Describes the development of the GNCC credentialing program. The book shows how to assemble and use a portfolio to verify competency in a specialty.
Statement on the Scope and Standards of Genetics Clinical Nursing Practice (1998) By International Society of Nurses in Genetics, Inc.	American Nurses Association	Scope and standards of practice for nurses in genetics

Genetics and the Perinatal and Women's Health Nurse (2001) By Judith Lewis	Association of Women's Health, Obstretric and Neonatal Nurses	This practice monograph provides nurses with the basic information they need to provide patients with accurate information about genetic screening and testing
Genetic Issues for Perinatal Nurses (2003) By Janet Williams, Dale Halsey Lea Editor Rita Reis Wieczorek	March of Dimes Birth Defects Foundation Education Services Dept	A nursing continuing education program that presents an update of genetics, principles of inheritance and ethical principles. Provides information on identification of actual or potential genetic conditions in the fetus, parent, or neonate.
The Nursing Clinics of North America: Clinical Genetics (2000) Editors Sharon Olsen, Lynn Baxendale- Cox, Victoria Mock	W.B. Saunders Company	The basics of genetics and genetic health care for the practice of every nurse and specialist
Cancer Care: A Guide for Oncology Nurses (2002) By Dale Lea, Kathleen Calzone, Agnes Masny, Annette Parry Bush	Oncology Nursing Press	A tool kit to assist the nurse in becoming competent in cancer genetics

# **Genome Research Resources**

Resource	Contact	Description
BLAST	http://www.ensembl	o Searches of protein or
	rg/Data/blast.html	DNA sequence
		against metazoan
		genomes
Cancer Genome Anatomy Project	http://cgap.nci.nih.g	ov Access to all CGAP
		data and biological
		resources
Chromosomal Variation in Man	http://www.wiley.co	M catalog of
	/legacy/products/sub	je chromosomal variants
	ct/life/borgaonkar/	and anomalies

Ensembl	http://www.ensembl.o	Access to DNA and
	<u>rg</u>	protein sequences
		with automatic
		baseline annotation
Human genome maps	http://genome.wustl.e	Links to clone and
	du/projects/human/ind	accession maps of the
	ex.php	human genome
National Center for Biotechnology	http://www.ncbi.nlm.	Views of
Information	nih.gov/genome/guide	chromosomes, maps,
	<u> </u>	and loci; links to
		other NCBI resources
Oak Ridge Genome Channel	http://compbio.ornl.go	Java viewers for
	<u>v/channel/</u>	human genome data
Online Mendelian Inheritance in Man	http://www.ncbi.nlm.	Information about
(OMIM)	<u>nih.gov/Omim/</u>	human genes and
		disease
The SNP Consortium	http://snp.cshl.org/	A variety of ways to
		query for SNPs in the
		human genome
UCSC Genome Bioinformatics	http://genome.cse.ucs	Reference sequence
	c.edu/	for the human and C.
		elegans genomes and
		working drafts for the
		mouse, rat, Fugu,
		Drosophila, C.
		briggsae, Yeast, and
		SARS genomes.

# **Appendix B:** Meeting Participant List

D.I.I.	LA ' NI A ' (' (ANTA)
Badzek, Laurie	American Nurses Association (ANA)
Beauchesne, Michelle	National Organization of Nurse Practitioner Faculties
Bickford, Carol	American Nurses Association (ANA)
Calzone, Kathleen, A.	International Society of Nurses in Genetics (ISONG)
	National Cancer Institute/NIH
Cashion, Ann, King	Un. of TN Health Science Center
Chornick, Nancy	National Council of State Boards of Nursing
Debisette, Annette, Tyree	DHHS/HRSA/BHPr/OAA
Feetham, Suzanne	DHHS/HRSA/Center for Quality
Fete, Mary	Dermatology Nurses Association
Geolot, Denise, H.	DHHS/HRSA/BHPr/DN
Goolsby, Mary Jo	American Academy of Nurse Practitioners
Greco, Karen, Elaine	Oregon Health & Science University
Hagan, Pam	American Nurses Association (ANA)
Hess, Madeleine	DHHS/HRSA/BHPr/Gec
Hickey, Joanne	American Nurses Credentialing Center (ANCC)
Jenkins, Jean, F.	NHGRI/NIH
Jungquist, Carla	American Society for Pain Management Nursing (ASPMN)
Kenner, Carole, A.	National Association of Neonatal Nurses
Kirk, Maggie	University of Glamorgan
	NMS National Genetics Education and Development Centre
Lea, Dale, Halsey	NHGRI/NIH
Lewis, Judith, A.	Virginia Commonwealth University
Littlejohn, Sandra	National Alaska Native American Indian Nurses Assoc.
Malloy, Pam	American Association of Colleges of Nursing (AACN)
Masny, Agnes	Oncology Nursing Society (ONS)
Messmer, Patricia, R.	NLNAC & Miami Children's Hospital
Moore, Mary, Kay	Developmental Disabilities Nurses Association
Mott, Sandra	Society of Pediatric Nurses
Nesseler, Kerry, Paige	DHHS/HRSA/BHPr
Olsen, Sharon	The Johns Hopkins University School of Nursing/SREB
Picard, Carol	Sigma Theta Tau International
Potempa, Kathleen	Oregon Health and Science University
Prows, Cynthia, A.	Children's Hospital Medical Center
Puetz, Belinda, E.	National Nursing Staff Development Organization
Ramirez, Carmen, T.	National Association Hispanic Nurses
Repta, Shirley	American Psychiatric Nurses Association
Rivera, Reynaldo,	Philippine Nurses Association of America
Ruhl, Catherine,	Association of Women's Health, Obstretric and Neonatal Nurses (AWHONN)
Rust, Jo Ellen	National Association of Clinical Nurse Specialists
Ryan-Kraus, Patricia	National Association of Pediatric Nurse Practitioners (NAPNAP)
Scales, Rosemary	Pediatric Endocrinology Nursing Society
Schiefelbein, Julieanne	The Academy of Neonatal Nursing
Schumann, Mary Jean	American Nurses Association (ANA)
Shaver, Joan	American Academy of Nursing
Shinn, Linda, J.	Consensus Management Group
Thomson, Elizabeth	NHGRI/NIH/ELSI Research
Tinkle, Melinda	National Institute for Nursing Research (NLN)
Valiga, Theresa, M.	National League for Nursing
Wicks, Terry, C.	American Association of Nurse Anesthetists
Williams, Charlene	American Academy of Ambulatory Care Nursing (AAACN)
Williams, Janet, K.	University of Iowa
Yeo, Seonae	Asian American/Pacific Islander Nurses Association
1 co, seoliae	Asian American/Facine Islanuel Nuises Association